Celiac Disease: An Overview and Personal Perspective

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OBJECTIVES:

At the conclusion of this presentation, the participant will be able to:
1. Define celiac disease, its symptoms and associated disorders.
2. Explain the tests used to diagnose celiac disease.
3. Explain the treatment of celiac disease.
4. Identify the current legislative measures and research studies associated with celiac disease.
5. List three challenges associated with following the gluten free diet.

Celiac Disease: An Overview

- Definition
- Symptoms
  - Complications
  - Associated Diseases/Syndromes
- Diagnosis
- Treatment
- Legislation
- Research/Clinical Trials
Celiac Disease: A Personal Perspective

- Diagnosis
- Challenges
- Shopping
- Food Preparation
- Eating Out

Celiac Disease: An Overview

- Definition: an autoimmune genetic disease caused by an ingested trigger
  - Autoimmune: ingestion of the trigger causes a response resulting in damage of small intestine
  - Genetic: predisposition linked to HLA-DQ2 and HLA-DQ8 genes
  - Ingested trigger: Proteins in wheat, barley, and rye

[Diagram of gluten-related disorders]
Celiac Disease: An Overview

Facts and Figures

Chance of developing CD
- Average healthy person: 1 in 133
- In people with related symptoms: 1 in 56
- People with 1st degree relative: 1 in 22
- People with 2nd degree relative: 1 in 39

www.celiacdisease.net

Celiac Disease: An Overview

Facts and Figures

- CD affects at least 3 million Americans with 83% undiagnosed (1% of healthy, average Americans)
- Average length of time to diagnosis: 4 years
- No age barrier
- Usually involves a “trigger”

www.celiacdisease.net

Celiac Disease: An Overview

- Symptoms: More than 200
  - Common
    - Abdominal pain/bloating
    - Diarrhea/constipation
    - Weight loss
    - Pale, foul smelling, fatty stools
    - Vomiting
  - Uncommon
    - Unexplained Fe-deficiency anemia
    - Fatigue
    - Bone/joint pain

www.digestive.niddk.nih.gov
Celiac Disease: An Overview

- Uncommon symptoms (cont.)
  - Canker sores
  - Dermatitis herpetiformis
- Silent/No Symptoms
- Long-term complications
  - Anemia
  - Osteoporosis
  - Miscarriage/fertility issues
  - Liver disease
  - Intestinal cancers

www.digestive.niddk.nih.gov

Celiac Disease: An Overview

Rare Complications of Celiac Disease

- Refractory Sprue
- Ulcerative Colitis
- Lymphoma

www.uptodate.com

Celiac Disease: An Overview

- Associated Autoimmune Diseases
  - IDDM
  - Graves Disease
  - Hashimoto's Thyroiditis
  - Sjogren's Syndrome
- Associated Syndromes
  - Down's Syndrome
  - Turner's Syndrome
  - Williams Syndrome

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Celiac Disease: An Overview

Diagnosis—All tests must be done with pt on normal diet

- Lab tests
  - Tissue transglutaminase antibody (tTG), IgG
  - Glutin Antibody, IgA
  - Total IgA
  - EMA titer
  - DGP

  Other possible tests: ion, folic acid, Ca++, Vitamins D, K, B-12

Celiac Disease: An Overview

- Biopsy
  - Done via upper endoscopy
  - 6 biopsies from distal duodenum

Celiac Disease: An Overview

Normal small intestine
Celiac Disease: An Overview

Normal Small Intestine and Histology

Small Intestine: lack of villi, scalloping and celiac disease histology

Treatment: COMPLETE and LIFELONG elimination of gluten from diet

- Gluten free diet
  - Avoidance of wheat, barley, rye, and oats
  - Obvious sources: bread, pasta, cereal, beer
  - Hidden sources: NUMEROUS
    - Canned, frozen, dry packaged items, pre-cooked foods
    - Non-food items: communion wafers, lipstick, play dough, meds, stamps, envelopes

www.celiac.org
Celiac Disease: An Overview

Foods to Avoid
- Obvious wheat sources: flours, bran, gluten, starch, germ/oil
- Malts: flavoring, extract, milk, syrup, vinegar, beverages (beer/wine coolers)
- Barley: malt, extract
- Rye
- Miso, matzo, graham flour, farina, couscous, cracker meal
- Bulgur: wheat, nuts
- Breads/rollins \* must be GF
- Cereals
- Hydrolyzed: oat starch, wheat gluten, wheat protein

Celiac Disease: An Overview

Gluten free Diet (cont.)
- Allowable foods
  - Fresh meat, vegetables, fruits, and dairy products prepared with allowable ingredients
  - Safe grains and starches
    - Quinoa, Nut flour, Soy
    - Millet, Tapioca, Potato
    - Rice, Bean, Buckwheat
    - Corn, Amaranth, Teff flour
- Certain canned, frozen, dried, packaged foods
- Cross Contamination

Celiac Disease: An Overview

- Amount of gluten in the average diet: 10-40gm/day
- Smallest amount of gluten to cause damage: 0.1mg/day = 1/48th slice of bread
- Amount of tolerable gluten: 1/8th teaspoon of flour per day
Celiac Disease: An Overview

Education
- Dietary consult
- Support Groups
  - National
  - Local
- Internet sites

Celiac Disease: An Overview

Improvement of symptoms
Within days/weeks
- Healed Small Intestine
  - 6-18 months (up to 2 years for adults)
- Normalized Antibody Levels
  - 3-12 months
Follow up (controversial)
- 3-6 months after diagnosis
- 1 year after being on gluten free diet
- Annually

Celiac Disease: An Overview

Legislation
- The Food Allergen Labeling and Consumer Protective Act (FALCPA)
- Voluntary Definition of "gluten free" on product labels
- HR 3648: Gluten in Medicine Disclosure Act of 2015
- Americans with Disabilities Act (504 Plan)
- Celiac disease is a disability
- USDA Child Nutrition Division
- School Lunch Guidelines
Celiac Disease: An Overview

Clinical Trials
Many studies in various stages throughout the world
- ALV003 (protease)
- Luseco prostate acetate
- Inoculation with Human Hookworm

Published Study
"Increased Prevalence and Mortality in Undiagnosed Celiac Disease" (Gastroenterology 2009; 137:88-93)

Celiac Disease: A Personal Perspective

- Diagnosis

- Challenges
  - Shopping/Cost ($$$)
  - Food Preparation
  - Eating out

Celiac Disease: A Personal Perspective

Shopping
- Loaf of bread $5.00-$8.00
- 4 hamburger buns $4.00-$7.00
- Flour blend $5.00/pound
- Cold Cereal Varies
- Chocolate cake mix $3-$5/box
- Spaghetti (corn, rice) $2-$4/12 oz
- Quinoa elbow macaroni $2.50/8 oz
- Xanthan gum $12.00/8oz
Celiac Disease: A Personal Perspective
Shopping (continued)

- More traditional foods available
  - General Mills®
  - Betty Crocker®
- Better food labeling makes shopping easier

Celiac Disease: A Personal Perspective
Cooking/Baking

- Utensils: cross-contamination
- Recipes
- Flours/flour blends
  - Commercial flour blends
  - Homemade flour blends
  - Individual flours
    - Soy flour
    - Tapioca starch/flour
    - Potato starch/flour
    - Brown rice flour
    - Xanthan gum
    - Rice flour

Celiac Disease: A Personal Perspective
Eating away from home

- Restaurants
- Potlucks
- Cafeterias
  - High School
  - College
  - Hospital
Celiac Disease: A Personal Perspective

Gluten Free Restaurant Dining Tips

- Be selective about type of restaurant
- Prior contact with restaurant staff
- Avoid peak times
- Bring “Plan B” item
- Tell Server right away
- Articulate dietary restrictions
- Narrow your choices
- Ask questions
- Discuss possible hidden gluten
- Confirm order upon arrival to table
- Express appreciation

Celiac Disease: A Personal Perspective

Potlucks

- Ingredients of ingredients
- Plan on not being able to eat much
- Cross-contamination
  - When in doubt, don’t eat it

Cafeterias

- High School
- College
- Hospital
Celiac Disease: A Personal Perspective

Conclusion

- Be knowledgeable about the disease
- Don't minimize the disease
- Ask patients their preferences/suggestions
Celiac Disease: An Overview and Personal Perspective

The Silver Lining

RETURN OF VILLI

Families living with Celiac Disease: happy and healthy
Thank You!!